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Patient Groups Assess the Patient Card
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A Participation Project
to Technology Assessment in Medical Informatics

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1) Technology Assessment on Patient Chipcards - A Must or Just Luxury ?

With the introduction of the health insurance card the era of chipcard technology in the health care system is beginning in Germany. Simultaneously with this administrative application there are several projects in the medical field to research and test extended forms of usage of chipcards. Some examples are special purpose cards for dialysis and cancer patients, but there are also several applications for the whole population like the pharmacy card. One of the first German pilot projects is starting next month in Neuwied and is called the »Modellprojekt Patientenkarte Koblenz« (»pilot project patient card Koblenz«) [Sembritzki: 1995].

The main argument for the development of medical card systems is - always - the benefit for the patients [Köhler 1994]. But there is no broad consensus about it in society, the introduction of these systems is not assessed positively by all social groups. For instance, the German »association of alternative patient offices« demands a moratorium for the health insurance card to discuss social chances and risks of card systems. This association is doubtful about the advantage of patient cards for the patients and is afraid of the worst case scenario, the complete control of physicians and citizens by health insurance organizations and the public health authority ([Gesundheitsladen Köln: 1994], [Bertrand, Jonas, Kuhlmann, Stark: 1995]).

With these chipcard systems fundamental structures of the German health care system will change [Geiss: 1994]. It is difficult to assess all social effects and interactions of a new chipcard technology in time, that means before the technology has penetrated all institutions irreversibly. The social-compatible development of card systems is possible. But how can Technology Assessment help to develop such systems more social-compatible? Is (participative) TA a must or just luxury?

2) Innovative Genesis Research and Participative Technology Assessment

The study of the social and technical processes of the origin - the genesis - of the chipcard technology in health care systems can be helpful for its technology assessment in time, because it doesn't focus only on the speculative after-effects, but on the "genome" of the technology [Rammert: 1993] - the actors, their interests, and their behaviour. The identification of the relevant social actors and the analysis of their behaviour and interests can help to ask the appropriate questions in technology assessment - before the farreaching diffusion of this technology in society is achieved. It is important to examine the actors and their interests in the arena of card system development in time. Then it may be possible to say something about the social, legal, and technological consequences of the introduction of card technology in the health care system and public health. The Policy Network Analysis is possibly one good method for an adequate analysis [Schneider, Werle: 1991].

Research on the genesis of chipcard applications is also necessary for participatory assessment and development, i.e. the active share of the social groups concerned by patient cards. They must be identified and encouraged to participate in this process. Then they have to articulate their interests explicitly and safeguard their interests against those of the other actors (i.e. [West: 1995] in another arena concerning employees and trade unions).

The open discussion about patient cards has not yet taken place in Germany. In other countries (e.g. Denmark) the discussion about »citizen cards« and other kinds of cards is already ongoing [Stripp: 1994].

For these reasons it is planned to organize a workshop in november 1995 in Koblenz. Representatives from several patient groups will come together to begin the assessment of the »pilot project patient card Koblenz« - explicitly from the perspective of the patientgroups.

The main aim of our research project on participation is to answer the question, whether a participative, i.e. a more basisdemocratic chipcard development is possible - and how to do it practically. Perhaps in future it will be normal to integrate participative elements in technological projects.

3) The Network of Shaping the Patient Card: Actors and Interests

There are different actors in the field of technical and organisational formation, each with its own interests and strategies to steer this social process of shaping chipcard technology : There are several groups who push chipcard systems (i.e. health insurance organizations, industry, research). But there are also several social groups (i.e. alternative patient groups), who are resolutely against the forced introduction of chipcard technologies in health caresystem. And there are also important groups who have no idea what happens (i.e. the patient groups). In this social field chipcard applications get their shape.

The following questions can help to identify the relevant actors and their interests:

- * To whose advantage ?
- * To whose interest ?
- * Under which conditions ?

I want to scatter the actual situation on actors and interests concering the patient cards - with a sideglance on the »pilotproject patientcard Koblenz«.

*** Industry:**

The European card industry is the technologically leading group on this technology. Naturally they want to sell all the basic products of the card technology. They also develop complete ready-to-use applications for several purposes. The chipcard field is a new, fast growing market. They hope to increase the sales worldwide from now 350 million dollar up to 1 billion dollar in 1998.

The medical chipcard pilot projects are a very good test field to prove and improve concepts - and to take the new market in time. The health care system is also fine for the introduction of a new technology: Social acceptance is high in this field.

The industry actually sponsors several pilot projects in Germany generously - especially in the Koblenz project several companies sponsor the cards, the card-readers, and the software which are delivered free of charge.

*** Representants of the Medical Profession:**

The main association of the settled physicians in Germany, the »Kassenärztliche Bundesvereinigung« (KBV) in Cologne, currently coordinates several card systems in the German health care system. In the Koblenz project, the KBV is carrying out the realization and the assessment ...

The doctors want to lead the shaping process (O.P.Schaefer, member of the KBV executive board, in [Maus: 1995]). A potential alternative coordinator could be the "competitor" »health insurance organization« - that wasn't very attractive for the doctors. Their main interest is to improve the working conditions for their members and to avoid control by insurance and public authority. Chipcards and computers can be used very well for controlling the quality and the efficiency of the medical business. So it is obvious why the physicians want to control the shaping process. Officially they only want to improve the treatment of patients by better communication techniques. By the way: The »Kassenzahnärztliche Bundesvereinigung«, the main association of our settled dentists, is strictly against cardsystems and electronic data exchange. Officially they fear the control of the patients by health insurance and industry.

*** Health Insurance:**

Their basic interest is to reduce costs in the health care system and to improve the quality of medical treatment. Rationalization of the administrative processes, control of costs, and detection of misuse and bad quality in treatment are their methods to reach both aims.

Officially they are the direct representatives of the patients, but reality is different [Wanek: 1994]. Interested people don't have much influence in these "modern service enterprises".

The health insurance organizations are not involved in the pilotproject in Koblenz. The different organizations plan their own particular card projects in the next time. The commissioner of data protection and privacy in Saxony said that several card projects of the health insurances are only "marketing gags". They want to achieve good positions for the new competition in the health insurance market in 1996 - patients' interests play not the main role in their decisions (Giesen's standpoint is described in [Görlitzer: 1995]).

*** Other Professionals in the Health Care System:**

The pharmacists have developed an own chipcard application for medication, the A-Card. Officially their interest is to strengthen the pharmacists role in the treatment of the patient. But the political pressure to keep the competence on the drug market also plays an important role. The A-Card is wanted to play a powerful role in pharmaceutical care.

The main association of the German pharmacists is one partner in the pilotproject in Koblenz. The A-Card is one element in this pilot project.

*** Research:**

Research in Medical Informatics is focused only on the technical and organisational aspects of the card-applications. Researchers in Medical Informatics generally feel no competence in the research of the social aspects.

*** Data-Protection and Privacy:**

The federal working group of the German commissioner of data protection and privacy has formulated a strict resolution concerning medical chipcards. The commissioner of Rhineland-Palatinate controls the pilot project in Koblenz.

The focus of the present work, however, lies on the main group involved in the health care system - the patients: They are the main target group for using patient cards. Yet there are very different patient groups:

*** Unorganized Patients**

The main group of the patients. It is difficult to reach this group for participation.

*** Bundesarbeitsgemeinschaft »Hilfe für Behinderte« (BAG HfB) (National Working Association »Aid for Disabled Persons«)**

The BAG HfB is the main national parent organization for the interest groups of patients and disabled persons in Germany. Over 50 organizations are represented in the BAG. Individuals cannot be members. The BAG is the lobby organization of several patient interest groups in politics. The BAG self itself is therefore no target group for our workshop, but only its particular member-organizations.

*** Allgemeiner Patienten-Verband (General Patient Association)**

This is a nationwide association for individuals, which is open to every citizen. It safeguards the interests of its members against the other actors like physicians and health insurance organizations. The main working field is counseling of the members. However, the association also complains against some structural problems in the health care system.

It is interested in participation, because it is sensible for questions concerning the structural problems in our health care system. It is familiar with political work and methods and is able to formulate its specific interests as patient group.

*** Patient-oriented Self-Help Associations and Groups**

- »First Contact«-Offices, like "AIDS-Aid"
- Talking Groups, like "Anonymous Alcoholics"
- Therapy groups, like "Society for Haemophiliacs"
- Legal assistance, like "General Patient Union"

They are interest groups coping with special aspects of injuries of health. It may be difficult to interest them for our participation project, because partially they are only sensitive to questions of their own direct interest, not to such special external fields like chipcard development. But when they realize the relevance of their participation, it might be possible to activate them for our participation workshop.

These patient-oriented groups are the main target groups for our workshop in the region of Koblenz and Neuwied.

* PatientInnenstellen and Gesundheitsläden (Alternative Patient Offices and Health Stores)

In the 80ies, some alternative ("green") people wanted to initiate a new medicine on a more democratic foundation. Therefore they opened self organized Health Stores in several German cities. Their main working field is counseling people with legal or medical problems. However, they also criticize the established medical business and formulate alternatives.

In 1994, they began to ask for open social discussion of new technologies in the health care system, especially of the medical chipcard technology. The association of »Alternative Patient Offices« in Germany therefore demanded a moratorium for the health insurance card in 1994. They started two "sample-letter"-actions to the health insurance organizations.

These offices are qualified for participation, because they are very interested in the structural problems of our health care system. But it is difficult to interest them for our project, because they are definitely against chipcard technology. They do not want to assist the development of this technology - in any way. They want to discuss real nontechnical alternatives and new structures of the health care system, not details of the medical chipcard.

Are there ethical limitations ?

For our participation workshop it is difficult to find suitable persons. Is it ethically legitimated to invite people who are possibly very sick and suffering? Is there a risk to overcharge the participants? Because of these questions we contacted different associations, because their members are accustomed to discuss the problems of the health care system and to formulate own political viewpoints.

4) Participation Workshop in Koblenz: Impulses for Social Discussion and Assessment

Inadequate participation : The big deficit ?

The citizens and the patients constitute the biggest group in the health care system. Officially they have the biggest lobby: Everyone wants to speak for this group, and wants to help: "Everyone is patient and is allowed to act in this role".

But is this deputyship legitimated in any way ?

Our workshop in Koblenz should contribute to remedy this grievance [Stark, Schmiede: 1995]. The main idea of our research work is, that citizen- and patientgroups should be encouraged to formulate their own interests and act for themselves. Several local patient groups should send participants to our workshop to begin the public discussion on patient chipcard applications and the chances of participation - in time with the beginning of the pilotproject in Neuwied. They should discuss together in the working group and with the experts of different backgrounds about the different aspects of chipcards and participation.

At our workshop it is not possible to perform a complete assessment of card systems in medicine. The time is too short and the theme too complex. But on the workshop we can try to answer following question:

Is it reasonable (and how is it possible) to constitute a patient working group, which engages on the assessment and development of the »pilot project patient card Koblenz« ?

This group should develop constructive ideas, proposals, and alternatives for shaping the organizational and technical structures of this concrete chipcard project. Our hope is that the ideas of this group represent the explicit interests of the patient groups. This would be possibly one step in the direction of more democratic structures in our health care system.

If this question is answered positively, we must also answer the question, how it is possible to constitute such a working group? Who will be the participants? What are the adequate structures of such a group? Who will have to pay for it?

The concept of our workshop in Koblenz is clear :

- * There will be 12 participants from local self-help groups and other politically active groups, who have possibly no idea what participation means and what a patient card is.

- * Therefore there will be short lectures on several aspects of participation and patient chipcards: These are concepts of participation, card-technologies and concepts, aims of the different actors in the pilot project Koblenz. Several experts will be invited to talk about these aspects, easy to understand for laymen.

- * But most of the time the participants will have to work with themselves. In a Future Workshop (concept with regard to [Jungk, Müllert: 1993]) they have to answer the question, which problem concerning inadequate participation is the worst. Then they have to formulate positive ideas and phantasies against that problem. Finally they have to test these ideas against the reality and they have to find concrete ways to go.

- * If the working group will receive a positive result, we must deal with the question, how to implement these ideas. In the last phase of our workshop the participants will discuss with several experts of the pilot project Koblenz and other on a roundtable, how to run a working group in cooperation with the »pilotproject patientcard Koblenz«.

Can participation (and how can participation) help to find adequate solutions for the problems in our health care system ?

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